

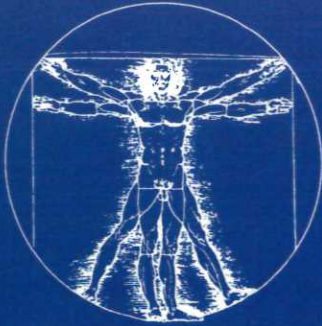
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Winter 1995

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

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GENETIC TECHNOLOGIES: ISSUES FOR ETHICS COMMITTEES

The Human Genome Project has identified hundreds of genes associated with human diseases. Often, diagnostic kits for detecting the presence of such genes are available for clinical use within months or even weeks of identification of the gene. As with any set of new technologies, the application of genetic technologies in the clinical setting has potential ethical pitfalls.

State of the science: genetic diagnostics and gene therapy

Applications of genetic technologies to medicine are in the areas of genetic diagnostics and gene therapy. Therapies aimed at treating inherited disorders raise many ethical issues that have been discussed at length elsewhere,⁽¹⁾ but will not be included here because these technologies are still limited to experimental use.

In contrast, genetic diagnostics are now used routinely in a variety of clinical settings to detect genes that cause disorders such as Gaucher's disease, Duchenne muscular dystrophy, or familial forms of breast and colon cancer.

As with any medical technology, many of the ethical issues raised by genetic diagnostic testing arise in deciding whether to use the technol-

Letter From the Editor

This issue of the newsletter is dedicated to the ethical issues raised by the ever-expanding reach of genetic technology. Many ethics committees may not as yet have been called upon to grapple with these issues, however, it is likely that committees will begin to see cases involving genetic issues in the not too distant future. As always, a well-informed ethics committee seems like an excellent forum for dissection of the issues raised by this technology. It is our intent, therefore, to contribute in a small way to the enlightenment of the subject, which is so essential to assisting both patients and providers, in making very difficult (and often controversial) choices.

Janice P. Rosenzweig

ogy. The nature of genetic tests, and the impact of the tests on the individual should be taken into consideration in these decisions. However, benefits and risks of most genetic diagnostics have not yet been well defined or systematically examined, especially with regards to long-term patient outcomes and adverse effects.

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30 copies)

Janice Rosenzweig, J.D., Acting Editor
Diane E. Hoffmann, J.D., M.S., Editor
Nancy Zibron, Layout Editor

Contributing Editors:

Louis Breschi, M.D., Member, Ethics
Committee, Franklin Square Hospital
John Fletcher, Ph.D., Director, Center for
Biomedical Ethics, University of Virginia
Sigrid Fry-Revere, J.D., Ph.D.,
Independent Bioethics Consultant
Jacqueline J. Glover, Ph.D., Philosopher-in-
Residence, Director, Office of Ethics,
Children's National Medical Center
Edmund G. Howe, M.D., J.D., Director of
Programs in Medical Ethics, Uniformed
Services University of the Health Sciences
Sanford Leikin, M.D., Adjunct Medical
Officer, Office of Protection of Human
Subjects, National Institutes of Health
Joan Lewis, Coordinator, Washington
Metropolitan Bioethics Network,
D.C. Hospital Association
Steven Lipson, M.D., Medical Director,
Hebrew Home
Franklin Miller, Ph.D., Bioethicist, Member,
NIH Clinical Center Bioethics Committee
Jack Schwartz, J.D., Chief Counsel,
Division of Advice & Opinions,
Maryland Office of the Attorney General
Ian Sherk, M.D., Member, Fairfax Hospital
and Reston Hospital Center Ethics Committees
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Medical System
Peter Terry, M.D., Member, Johns Hopkins
Hospital and Francis Scott Key
Medical Center Ethics Committees
Jan Vinicky, Ph.D., Bioethicist,
Washington Hospital Center
Margot White, J.D.

**The Institutional Ethics
Committee Resource Network
Law & Health Care Program
University of Maryland School of Law
500 West Baltimore Street
Baltimore, MD 21201
410/706-7191 or 410/706-7239**

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University of Maryland
at Baltimore



NETWORK NEWS

Baltimore Area Ethics Committee Network (BAECN)

As a result of the December meeting which addressed the topic, "Standards for Ethics Committees," the network decided to establish two new working groups.

The first one will be a task force charged with the responsibility for drafting standards for qualifications and education of ethics committee members.

The second group will be a formal committee established specifically to offer, upon request, retrospective consultation review of hospital ethics committee decisions. Such review may be either in the form of written analysis or by way of dedicating an entire meeting of this committee to a discussion of the issues raised.

The membership of both the task force and the review committee is yet to be determined. Those members of any ethics committee who wish to serve on either of these two groups are encouraged to call Jack Syme, M.D., President, BAECN, at the Department of Neurology, St. Agnes Hospital, Baltimore, MD at (410) 368-3020.

Washington Metropolitan Bioethics Network (WMBN)

"Power Among Professionals: The Effects on Patient Care," was the topic of the network meeting held on January 28, 1995. Panelists for this program looked at the various relationships among different medical professionals and how those translated into ethical treatment of patients. The February meeting will be held on February 28, 1995 from 4:00 - 6:00 p.m. The topic is: "Chaos Theory, Split Brain Research and Other Reasons for Questioning Sacred Cows in Contemporary Medical Ethics Practice."

The network is currently planning its program schedule for 1995. Contact Joan Lewis at (202) 682-1581 if you have ideas for future topics.

Virginia Bioethics Network (VBN)

Edward M. Spencer, M.D., Director of Outreach, Center for Biomedical Ethics at the University of Virginia, announced that the next Developing Hospital Ethics Programs (DHEP) courses will be held from March 27-April 1, 1995 at the University of Virginia.

DHEP is an intensive 6-day course of study for health care professionals from hospitals and other health care institutions. It is designed to facilitate or strengthen the implementation of an ethics program within these institutions.

This unique course is limited to 24 participants so that interaction and networking will be possible.

For further information on the DHEP course, please call (804) 924-5974.

Bioethics Network of Southeastern Virginia (BNSE)

The Bioethics Network of Southeastern Virginia recently chose a new President, Joe Riddick, M.D., Pathology & Clinical Ethics, Chesapeake General Hospital and Adjunct Associate Professor at Eastern VA Medical School. Dr. Riddick can be reached at (804) 482-6118 or by e-mail at joeriddicinf.net.

A special program, "Saturday in Bioethics," set for February 4, 1995, will address the topic, "Prolonging Life in a Newborn or at the End of Life: Why do we? Who Benefits? Who is Harmed?" See Calendar on page 11 for details.

Genetic Technologies

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The nature of genetic tests

Genetic tests create the illusion of our being able to specifically pinpoint a medical problem with molecular accuracy. However, the diagnostic certainty that patients and doctors crave is not always delivered by these tests. Therefore, we have to consider the following issues in thinking about whether to use a test just because it exists:

◆ **How is disease defined, and who defines it?** The inability of a child to hear might be considered a disability to those who can hear, but might not be to the child's deaf parents, for example. Should disease be based on functional criteria, and if so, whose?

◆ **Mutations don't always mean disease.** For example, we may feel comfortable defining a mutation in the cystic fibrosis gene as causing disease if it leads to chronic respiratory infections from birth and death at the age of 25. However, a different mutation in the same gene might cause little or no problem - is this also cystic fibrosis? In addition, for many genes, the same mutation in different individuals can be associated with different levels of symptoms, but these differences can not necessarily be predicted. Other unknown aspects of an individual's genetic make-up and environmental factors also influence the outcome. Therefore, genetic tests open to interpretation can lead to the creation of medical "problems" where none exist.

◆ **If it is a disease, is there a "cure" for it?** Although many genes have been linked to diseases, virtually no new therapies exist for these diseases. The majority of those new therapies are improvements on non-genetic, "traditional" therapies. Therefore, at this stage, we have to consider the benefits of knowing (with varying degrees of certainty) that one has or might have a disease but not being able to do much about it.

◆ **Has the test been tested?** Just because a test exists or even if it is considered the standard of care doesn't mean it has been examined for safety and efficacy. Chances are that it has not. It might even have been adopted for widespread use against the recommendation of professional associations, as was the test for cystic fibrosis,⁽²⁾ These tests are not regulated by the FDA or other government agencies to the same extent as drugs.⁽³⁾

Risks and benefits to the individual

◆ **Physical benefits and risks.** With current techniques such as the polymerase chain reaction (PCR) for analyzing DNA from extremely small tissues samples, physical risks are minimal. However, physical benefits from the knowledge obtained can vary enormously. The extent of the benefits of a genetic diagnostic test depends on (1) what the severity of the disease is or will be, (2) whether there are palliative or therapeutic actions that can be taken as a result of a "positive" test result (i.e. disease is or will be present) and (3) whether preventable disease would have occurred in the lag time between the genetic diagnosis and the time the diagnosis would have been made by other means.

◆ **Psychological benefits and risks.** Knowledge from genetic testing can provide many psychological benefits, even if physical benefits are minimal. Testing can relieve anxiety, especially if the test has a negative result. Even testing positive for a disease can give a name to a problem, provide the opportunity to seek appropriate medical help, and help prepare for an eventual illness. However, the negative impacts range from depression and feelings of futility in people who test positive to "survivor guilt" in those who test negative. There are also complications caused by false positive and false negative test results.

◆ **Social benefits and risks.** Few social benefits of testing have been identified. However, many social risks of genetic testing have been identified and can occur even if the test is nega-

tive or indicates that an individual is an asymptomatic carrier. The risks include stigmatization, loss of health or life insurance, loss of employment or educational opportunities, and inability to adopt a child.

◆ Privacy and confidentiality.

Privacy and confidentiality may also be threatened if a family member gets a genetic test, and the results imply that untested relatives also have the disease, are at increased risk of having the disease, or of being a carrier. In addition, it is sometimes necessary to take samples from several family members in order to determine the genotype of one individual. Some family members may not wish to submit themselves to the physical discomforts and risks of giving samples. They may not wish to know their genotype, or may not wish others to know. Here, the autonomy of individuals is in conflict.

With the current state of genetic technology, genetic diagnostics might be less beneficial and more risky than commonly perceived. As ethics committees face problems of individuals raised by genetic tests, they need to be aware that even though a test is available or widely used doesn't mean that it *should* be used. Although they can be beneficial, genetic tests can violate an individual's autonomy, impinge on physical and mental health, and can take resources away from more effective uses. For example, a screening program for cystic fibrosis could cost over \$2,000,000 for every case averted.⁽⁴⁾ Therefore, committees should keep in mind that the sum of their individual decisions will contribute to the overall pattern of how these new technologies will be perceived and used in the future.

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Genetic Technologies

Cont. from page 3

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Submitted by:

Mildred K. Cho, PhD

Pew Post-doctoral Fellow
Center for Health Care Evaluation
Palo Alto VA Medical Center
Stanford University Department of
Health Research and Policy
Institute for Health Policy Studies
University of California, San Francisco

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Editor's Note: Due to the paucity of genetics issues currently being referred to hospital ethics committees in the region, and the attendant concerns for confidentiality, we depart from our usual format. The following case is a hypothetical one, presented for the purpose of examining the ethical issues raised by genetic technology.

Case Study

A couple, one of whom has Waardenburg syndrome, approaches a geneticist for help in having a deaf child. Waardenburg syndrome is a dominantly inherited condition that can be associated with deafness, as well as, facial defects that are variably expressed, such as early graying of the hair, a white forelock, heterochromia, wide spacing of the eyes or growing together of eyebrows.

Twenty to twenty-five percent of individuals with this syndrome have severe deafness, so that while a person with this disease has a 50% chance of passing this gene to each of their children, there is *only* a 10% chance that a child will have Waardenburg syndrome and be deaf.

This husband and wife view deafness as a "language problem rather than a

handicapping condition." This view is widely held among hearing impaired persons in the U.S. today. The "Deaf Pride" movement maintains that deafness is not a disease and that deaf persons are as qualified as others for any profession or occupation. This couple believes that they can more successfully raise a deaf child than a hearing child.

Using DNA technology, scientists have mapped the marker genes close to the gene that causes Waardenburg syndrome on chromosome 2 and believe that the ability to diagnose this disorder in a fetus in utero is imminent. This couple is willing to use selective abortion after prenatal diagnosis to achieve their goal of giving birth to a child with Waardenburg syndrome.

The geneticist discusses the couple's request with an obstetrician-gynecologist in the hospital who is skilled in prenatal diagnosis. Together, they decide to approach the hospital ethics committee requesting advice as to whether they should cooperate with the couple's wishes.

Submitted by:

John C. Fletcher, PhD.
Kornfield Professor of Biomedical
Ethics and Director of the
Center for Biomedical Ethics
University of Virginia
Charlottesville, VA

Based upon the conception of:
Walter Nance, M.D., PhD.
Chairman, Division of Genetics
Medical College of Virginia
Richmond, VA

Case Discussion: Comments From Two Physicians

This couple's request for fetal genetic screening for the purposes of ensuring the presence of a genetic disease and aborting any normal fetus poses interesting and challenging questions concerning the interests of the parents, child, medicine and society.

Choice for a deaf child

Our first concern is that the couple thoroughly understand the Waardenburg Syndrome (WS) disease spectrum. There are many disabilities other than deafness which occur in WS. Some of these conditions cannot be detected in utero. While they occur infrequently, many are devastating conditions such as myelomeningocele, Hirschsprung Disease, esophageal atresia with tracheo-esophageal fistula, vertebral agenesis, and absence of a vagina and right sided adnexa uteri.^(3,4,5,6,7) Other conditions include nasal atresia, cleft lip/palate, cataracts, microcephaly, imperforate anus, syndactyly, cardiovascular anomalies, urinary anomalies, and musculoskeletal abnormalities, including lack of development of the upper extremities.^(3,8) While deafness may arguably be classified as a communication disorder and not a disability, it is hard to classify the lack of upper extremities or paralysis secondary to myelomeningocele as anything other than a major disability.

The couple's physicians should thoroughly evaluate their understanding of the likelihood of deafness as well as potential risks to their child other than deafness. Salient areas to further probe would be: (1) their willingness to accept a child diagnosed in utero to have WS who is found to have normal hearing; (2) their willingness to accept other potential health effects of WS which can only be diagnosed after birth; (3) their consideration of the child's pain and risks of potential surgeries needed to correct functionally disabling or life threatening abnormalities which may occur in WS; (4) their emotional and financial ability to deal with conditions associated with WS other than deafness; and, (5) their plans for continuation of pregnancy or abortion if other conditions associated with WS are diagnosed in utero.

Another concern raised by the couple's request is what they mean by "more successfully raise a deaf child than a hearing child." It is important to investigate the factual and emotional basis for this statement. In our attempt to survey the literature on the topic of

disabled parents and child rearing, we discovered that there is a paucity of factual information. There was no evidence of studies which examined the success of deaf parents raising deaf children, or comparing the success of deaf parents raising hearing versus deaf children. There were several studies examining the rearing of hearing children by deaf parents. A study of Chinese children comparing the self-concepts of hearing children of deaf parents with the self-concepts of hearing children of hearing parents found no difference of self-concept in the children. It did, however, find that deaf parents had lower self-concepts than hearing parents.⁽⁹⁾ Another group found that hearing children of deaf parents adopted normal phonation compared to hearing children of hearing parents.⁽¹⁰⁾ We found only one reference which suggested that parental deafness might impact negatively on the child or familial relationships. The authors discuss "... role reversal leading to a frustration of the child's dependency needs and bitter sibling rivalry"⁽¹¹⁾ However, the scant information available suggests that deaf parents can successfully raise hearing children.

Parental choice vs. rights of the child

There is abundant ethical literature dealing with the rights of parents to be counseled about their risk of genetic disease and to be provided with the appropriate services, including abortion.^(12, 13, 14, 15, 16) These rights are supported by the principles of autonomy, informed consent and privacy.

However, with parental rights come parental obligations and responsibilities. The obligations of parents should limit parental choice. The "fiduciary" nature of the parental-child relationship requires that the parent promote the best interests of the child before their own.⁽¹⁷⁾ The parents should also provide the opportunity for maximal health and well being for their child and strive to limit situations which could be detrimental to their child. Accepting a genetic disease diagnosis, carrying a fetus to term and providing

the appropriate medical care and social environment post birth is consistent with ideal parental behavior. Intentionally seeking to obtain a genetic disease in a child is not.

The rights of the child who is the product of genetic counseling must also be considered. These would include health, well being, and the opportunity to live a life unencumbered by disease or disability. While a guarantee of disease or disability free life is impossible, it's in the child's interest not to intentionally seek these burdens.

Obligation of physicians

The traditional societal and professional mandate for all physicians is to identify and treat or cure disease and alleviate suffering.⁽¹³⁾

"The medical profession has earned respect through its persistent exercise of traditional ethical values that lead physicians to abhor death and to work hard to maintain and restore health. If the profession is to maintain credibility it must continue to demonstrate concern for the preservation of the lives of the sick and the weak. Eugenic abortion does not fit this ideal; its practice endorses a principle of rejecting defect that gives a non-medical (even antimedical) priority to parental, familial and societal claims to well-being over those of the person yet to be born."⁽¹⁸⁾

Currently, the only way to prevent a genetic disease that has been diagnosed in utero is to abort. However, this is not the primary goal of genetic medicine. Summarized, the goal of genetic medicine is to improve the health of the individual by identifying genetic diseases so that they may be prevented or treated before they adversely affect the health of the individual.^(14, 16) Genetic medicine is not to be used in the service of a government or society attempting to engage in eugenic

Case Comments

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campaigns, for the primary goal of improving the health of society as a whole, or for improving the normal human condition. We would add that successful treatment or prevention does not require killing the affected human at any stage in his/her development. One could argue that the couple's request to abort normal fetuses until they have a fetus with WS would be consistent with respecting the lives of the disabled or diseased. However, situations where genetic services are requested for the express purpose of guaranteeing the presence of a genetic disease are completely at odds with the primary goals of physicians and genetic medicine.

Society's interest

Genetic diversity is necessary for the continued health of the species. In fact, some genetic diseases provide survival advantages against other diseases, such as sickle cell trait providing a survival advantage against malaria. Our culture is still one which is highly dependent on the spoken and heard word and one can argue that hearing confers a survival benefit in the context of modern existence.

The cost of medical care and the just utilization of resources is of great concern. Society has an obligation to care for all its members who are diseased or disabled and to protect them from discrimination. But, its resources are finite. Intentional parental pursuit of disease or disability in a child, particularly if the parents cannot guarantee complete financial support and medical care for the lifetime of the child, is at odds with societal just resource allocation interests.

In conclusion, we find that there are significant concerns other than parental autonomy and choice which need to be considered in this case. We would, therefore, recommend that the couple's request be refused at this time.

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Submitted by:
Karen A. Korzick, M.D.
Pulmonary Fellow and
Peter B. Terry, M.D., M.A.
Professor of Medicine
Johns Hopkins University
Division of Pulmonary
and Critical Care Medicine
Baltimore, MD

Case Discussion: Comments From a Genetic Counselor

The central issues in this case involve patient autonomy and examination of the ethical/moral dilemmas that surround personal choice, as new technological options become available. It does raise relevant issues that warrant immediate discussions since research for several inherited forms of deafness is ongoing and the use of prenatal testing for "isolated" deafness may be available in the next few years. Should prenatal diagnosis and the use of selective abortion be allowed to achieve the goal of giving birth to a child who is deaf? (The term "deaf" is used to denote a person who audiologically has some degree of hearing loss. However, the term "Deaf" is used to refer to a person who is culturally deaf.) Who should decide? How does the hearing community feel; the Deaf community?

Ethical principles of genetic counseling

Since its inception, the field has relied on the basic principles that genetic counseling is educational and non-directive. The genetic counselor assists families in obtaining information in a supportive environment so that they can choose or act in a way that best fits their own values. The most prevalent guiding principle in genetic counseling is the belief that patient autonomy is most important; the patient has the freedom to make his/her own decisions. Over the last 20 years, genetic counselors have provided prenatal services for which there was a general consensus of what was considered "seriously disabling" or "life-threatening" conditions. However, over time, advances in medicine, treatment modalities and early intervention programs have provided new perspectives on what 10-20 years ago may have been considered a serious genetic condition or birth defect.

During this time of genetic technological advancements, many "disability"

groups and minority populations have been empowered. (Weiss, 1993) There is social and political acceptance and demand for recognition of these differences. The passage of the Americans with Disabilities Act (ADA) reflects this movement and the value and acceptance of diversity in this country (Pray, 1994).

Deafness: disability vs. cultural difference

Individuals who experience some degree of hearing loss form a diverse group consisting of varied backgrounds, experiences, linguistic differences and identities to hearing and Deaf cultures. Within this diverse group, deafness may be seen as a handicap or be defined as a cultural difference where members are bound together by common history, language, experiences and values. Padden and Humphries (1988) explain,

... "disabled" is a label that historically has not belonged to Deaf people. . . .when Deaf people discuss their deafness, they use terms deeply related to their language, their past and their community" (p.44)

Individuals who are culturally Deaf do not view their deafness as a handicap but have a great sense of pride in being Deaf. These beliefs may be reflected in a Deaf person's values on marriage and family. Deaf individuals may feel that it would be more desirable to have deaf children because of the strong desire to preserve Deaf culture and because of the communication/language bonds that will develop (Bienvenu and Colonius, 1985). Since deaf children may be preferred, hearing children may be considered a "risk".

Genetic counseling and deafness

If we apply the principles of patient autonomy and respect for our client's beliefs and cultural values, then shouldn't the option of prenatal diagnosis with consideration of selective termination of a hearing child be given the same consideration as

performing prenatal diagnosis for hearing parents who do not want a deaf child?

There are many issues to be addressed with this couple in genetic counseling. These may include: are they prepared to accept a hearing child who has Waardenburg syndrome or would they consider placing this hearing child for adoption? Since it is possible that a hearing child who has Waardenburg syndrome may pass this gene to his/her children who could be deaf, this couple may feel this is an acceptable option, and a way of preserving Deaf culture. Alternatively, would this couple consider adopting a deaf child to achieve their parenting goals?

A similar case example involving deafness was posed to patients through a survey at 4 sites in the United States and Canada (Fletcher and Wertz, 1988) Results of this survey showed that approximately 60% of patients agreed that the request of prenatal testing should be honored. These results (and the overall results of the pilot survey) reflect the overriding value that is placed on client autonomy even when faced with difficult ethical/moral issues.

Several well-respected geneticists argue that we must abandon our value neutral ties and non-directiveness in the face of what may be considered trivial requests for the detection of traits that are "unrelated to health and well-being issues" (Murray, 1992). Nance (1993) comments on this issue: "others with whom I have spoken feel that to assist a deaf couple in having a deaf child would not only be dysgenic, but would constitute a perversion of the process of genetic counseling." Caplan (1993) maintains that "value neutrality leaves counselors powerless in the face of what may be immoral requests on the part of clients." Is it immoral for deaf parents to believe that they can be more competent parents to a deaf child who can share the same linguistic and cultural values? If we allow prenatal diagnosis for deafness to be offered only to hearing parents who desire only

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Case Comments

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hearing children, what moral judgments are we making? Do we develop guidelines that prenatal diagnosis for deafness not be made available, since it may not be considered a "serious" condition by some?

Most recently, members of the American Board of Medical Genetics, American Board of Genetic Counseling and Canadian College of Medical Genetics were sent a questionnaire to study current practices among genetic professionals concerning the meaning of a "serious" genetic condition or birth defect. These researchers (Wertz et al, 1994) question whether there should "be an official list of disorders that are sufficiently serious to warrant carrier testing or prenatal diagnosis" since more policy statements concerning genetic testing use language such as "serious", "high risk" or "lethal".

The development of such a list raises a whole host of issues and concerns about the value of patient autonomy and personal choice: who should be making the decisions, what are the social, legal and political ramifications if we choose one option over another? And, who will be paying if we make certain choices? With the implementation of health care reforms, what role will insurance companies, health maintenance organizations and other third party payers have in these decisions? Where would deafness fall on this list? These are difficult issues that must continue to be on the forefront of discussions for health care providers and consumers, as we walk the tightrope of utilizing technological advances, while at the same time embracing and empowering diversity and patient autonomy.

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Submitted by:
Jamie Israel, M.S.
Genetic Counselor
Genetic Services Center
Gallaudet University
Washington, D.C

MARYLAND COURT OF APPEALS SENDS MIXED MESSAGE ON GENETIC TESTING

In *Reed v. Campagnola*, 332 Md. 226 (1993), the Maryland Court of Appeals definitively stated that this State does recognize a wrongful birth cause of action concerning a physician's obligation to advise parents of the existence, availability, and/or advisability of genetic testing.

The *Reed* case involved a pregnancy which resulted in the birth of a child with an open neural tube defect and other congenital anomalies. The parents were not apprised of the existence or availability of maternal serum alpha-feto protein (MSAFP) testing which, if performed, would have probably resulted in the discovery of the neural tube defect. With this information, the parents would then have had the option of continuing or terminating the pregnancy. The *Reeds* brought a wrongful birth cause of action against the family practice physicians who were providing Mrs. Reed's prenatal care. This cause of action was based both on a negligence theory and an alternative informed consent theory. The Court permitted the negligence cause of action but rejected the informed consent theory.

The differences between the two theories, negligence and informed consent, are significant. In order for a plaintiff to prevail on a negligence theory, the plaintiff must prove that it was the standard of care for physicians to apprise the expectant parent of the availability of AFP testing. Further, the plaintiff must prove that the physician breached the standard of care and caused the damages. Expert testimony establishing the applicable medical standard of care is required under a negligence theory.

The Court, however, rejected an alternative informed consent theory of negligence. Under an informed consent theory in Maryland, the critical issue is not whether or not it was a

medical standard to apprise or advise the expectant parent of the availability of AFP testing, but rather whether or not a reasonable person would find this information to be material (or significant enough) to them in determining whether or not to continue or terminate a course of treatment. No medical expert testimony is required for a plaintiff to prevail on an informed consent theory of negligence. The *Reed* Court correctly surmised that the Reeds sought to establish a rule that the appropriate tests for predictive genetic counseling would be determined by what reasonable persons, similarly situated to the plaintiffs, would want to know. The Court rejected this standard, however, in favor of allowing the medical community to make the determination of what tests should be disclosed.

It is also interesting to note that Mrs. Reed's obstetrical care was being provided by family practitioners in a county health department. These physicians testified at deposition that they could not have offered or apprised the Reeds of the availability of AFP testing, because they themselves were not aware of this testing. They further testified that they were not obligated to follow American College of Obstetrics and Gynecology (ACOG) standards or guidelines because they themselves were not obstetricians. They also testified that they did not feel any disclosure to prospective parents was necessary and even though they were offering obstetrical services, as family practitioners they did not have to follow the same standards as obstetricians. This raises troublesome questions concerning the knowledge and standard of care applied to generalists practicing obstetrics. With the increasing prevalence of managed care health systems and more and more reliance on primary care physicians, the "adequate knowledge base" question becomes critical.

Despite the failure of the Court to recognize an informed consent theory of liability in the area of prenatal genetic testing, the *Reed* decision is a clear call to physicians practicing

obstetrics to heed the existence and availability of prenatal genetic testing. With continuing advances and breakthroughs in human genetics and with the rapidly expanding knowledge base underlying these advances, the need for continuing education for both primary and specialty care physicians is critical. Physicians must stay well ahead of their patients in their education concerning these tests. The popular press latches on to fragments of information concerning advances in genetics and frequently publishes "soundbites" which may or may not leave patients with proper information. It is incumbent upon health care providers to properly inform their patients about the limitations of available genetic testing.

As the plaintiff's attorney in the *Reed* case, we share the view of many experts in the field that litigation in the area of genetic testing will be expanding, not only in the area of malpractice cases, but also in insurance and discrimination claims.

Submitted by:

Diane M. Janulis, Esq.
Cowdrey, Thompson & Karsten, P.A.
Easton, MD

Editor's Note: Ms. Janulis is a graduate of the Law and Health Care Program at the University of Maryland School of Law.

UNIVERSITY OF VIRGINIA SURVEY FINDS SUPPORT FOR LIMITING END OF LIFE MEDICAL CARE

The Center for Biomedical Ethics at the University of Virginia conducted a telephone survey of 503 adults in that state who were asked to evaluate eleven vignettes that presented randomly assembled, but plausible, cases of terminal and catastrophic illness. Each respondent was asked to make a recommendation to continue or stop expensive care that had limited or no medical benefits.

The results of the survey indicate that a majority of the respondents (77

percent) supported terminating treatment when life expectancy was less than one week or when the patient was permanently comatose or unconscious, even when advance directives were not present. More than half also supported stopping treatment in the cases where the prognosis was severe disability, even when life expectancy was significant. In vignettes without advance directives, respondents recommended treatment be stopped 45.5 percent of the time overall.

In cases where there was an advance directive which said that the patient did not want to live under the circumstances of the vignette, there was a significant increase (39 percent) in the recommendation to terminate treatment. This finding was consistent across major religious groupings and attitudes about abortion.

In general, however, the survey indicated that religion, race and age did affect respondents' recommendations to stop treatment. Evangelical Christians were much less likely than average to recommend terminating treatment, while Protestants were more likely to make such a recommendation. Catholics were indistinguishable from the average. African-Americans were almost 30 percent less likely than the average to suggest that treatment be stopped. Men and women did not differ significantly in their decisions regarding treatment, but the older the respondent, the more likely they were to recommend treatment be terminated.

The survey found that approximately 20 percent of Virginians have a written advance directive on end of life decisions, which is consistent with the findings of studies which show that between 17 and 24 percent of Americans now have advance directives.

"HARD CHOICES FOR LOVING PEOPLE"

A & A Publishers announced the publication of the third edition of the booklet, "Hard Choices for Loving People" by Hank Dunn. The pamphlet is currently being used by over 2,000 hospitals, nursing homes and hospices throughout the U.S.

This new 48-page edition is subtitled, "CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient," and is addressed to elderly patients and their families, although it is applicable to any patients in life-threatening situations.

Incorporating the latest research regarding end-of-life decisions and the frail patient, this 1994 revision covers such issues as: dehydration in the dying

patient, the benefits and burdens of hospitalization for the nursing home resident, and the hospice approach to patients in the end stage of any disease.

Hank Dunn has served as the full-time chaplain at the Fairfax Nursing Center in Virginia for eleven years.

Copies of "Hard Choices" are available at a cost of \$2.25 each with discounts for bulk purchases from the publisher at P.O. Box 1098, Herndon, VA 22070.

NEW LECTURESHIP ANNOUNCED

The Office of Ethics and the Department of Pediatric Medicine are pleased to announce the first annual *Sanford L. Leikin, M.D., Lectureship in Pediatric Ethics*, to be held at Children's National Medical Center, in Washington, D.C., on February 1, 1995, at 8:00

a.m., in the hospital auditorium. This lectureship, established in recognition of Dr. Leikin's more than three decades of service to Children's, will support annual presentations by outstanding leaders in the field of bioethics.

The first guest lecturer is Howard L. Brody, M.D., Ph.D., speaking on "Ethical Issues in Managed Care." Dr. Brody is Professor of Family Practice & Philosophy and Director of the Center for Ethics and Humanities at Michigan State University. He is also the author of numerous publications, including such well-known books as *The Healer's Power* and *Stories of Sickness*.

Because the lectureship is part of the hospital's grand rounds series, Category I CME credit will be offered. For further information, call the Office of Ethics at 202/884-3291.

Book Review

WOMEN AND PRENATAL TESTING: Facing the Challenges of Genetic Technology

Edited by: Karen H. Rothenberg and
Elizabeth J. Thomson

This new book brings a refreshing perspective to the subject of reproductive and genetic technology. It is a perspective which has long been overlooked by the medical research community, the view of those who are most impacted by this new technology—women.

Through a comprehensive collection of scholarly writings by women, this book explores the issues involved in the ongoing, often emotionally charged, debate about the use and abuse of this technology. The preface to this work tells a personal story of a woman in prenatal crisis, placing the essays on medicine, philosophy, ethics, law, psychology and sociology, which follow, in a very real context.

This book is must reading for anyone, male or female, who may be called upon to effect the life and death decisions which prenatal testing and diagnosis represent.

The book is available from Ohio State University Press, 180 Pressey Hall, 1070 Carmack Road, Columbus OH 43210, (614) 292-6930, in paperback, at a cost of \$17.95 plus postage & handling.

CALENDAR OF EVENTS

FEBRUARY

- 4th Saturday in Bioethics, Topic: "Prolonging Life in a Newborn or at the End of Life: Why do We? Who Benefits? Who is Harmed?," 8 a.m.-1 p.m., sponsored by Bioethics Network of Southeastern VA at VA Beach General Hospital Health Education Center. Call Joe Riddick, M.D. at (804) 482-6118.
- 7th Bioethics Network of Southeastern VA Meeting, 7:00 p.m. Topic: "Pastoral Care and HIV," Auditorium, Hofheimer Hall, Norfolk General Hospital, Norfolk, VA. Call Joe Riddick, M.D. at (804) 482-6118.
- 7th Baltimore Area Ethics Committee Network Meeting, 4:30 p.m. Topic: "The Ethics Consultation Process," MD General Hospital, Baltimore, MD. Call Jack Syme, M.D. at (410) 368-3020.
- 9th Medical Humanities Hour, "A Literary History of the Definition of Death: From the Talmud to Nancy Cruzan," 1:00-2:00 p.m., Shock Trauma Auditorium, University of MD Medical System, Baltimore. Call Henry Silverman, M.D. at (410) 706-6250.
- 28th Metropolitan Washington Bioethics Network Meeting, Topic: "Chaos Theory, Split Brain Research and Other Reasons for Questioning Sacred Cows in Contemporary Medical Ethics Practice." Call Joan Lewis at (202) 682-1581.

MARCH

- 2nd-4th Fourth Annual Meeting of the Association for Practical Professional Ethics, Crystal City, VA. Call Brian Schrag at (812) 855-6450.
- 6th "Ethical Issues Raised by Managed Care," 6:15-9:15 p.m., a session within the "Management in the Managed Care Marketplace Certificate Program," Loyola College, Baltimore, MD. Call Janet Penn at (410) 617-2107.
- 9th Medical Humanities Hour, "Human Embryo Research: What Are the Appropriate Guidelines?" Steven Muller, President Emeritus, Johns Hopkins University, 1:00-2:00 p.m., Shock Trauma Auditorium, University of MD Medical System, Baltimore. Call Henry Silverman, M.D. at (410) 706-6250.
- 7th Bioethics Network of Southeastern VA Meeting, 7:00 p.m., Topic: "Ethics of Suffering," Auditorium, Hofheimer Hall, Norfolk General Hospital, Norfolk, VA. Call Joe Riddick, M.D. at (804) 482-6118.

APRIL

- 4th Baltimore Area Ethics Committee Network Meeting, 4:30 p.m., Topic: "Futility," 4:30 p.m., North Arundel Hospital, Glen Burnie, MD. Call Jack Syme, M.D. at (410) 368-3020.
- 5th Bioethics Network of Southeastern VA Meeting, Topic: T.B.A. Call Joe Riddick, M.D. at (804) 482-6118.
- 19th West Virginia Bioethics Forum, Topic: "Ethical Issues in the Care of the Dying," Byrd Health Science Center, University of West Virginia, Morgantown. Call Cindy Jamison at (403) 293-7618.

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